

Presidential Address

To Be or Not to Be? That Is the Question

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First, let me rest your minds that the title of my talk does not refer to the well-being of the American Society of Human Genetics. We are not near bankruptcy; we are not involved in a merger or a dissolution. Instead, the title, TO BE OR NOT TO BE?, refers to whether or not a defective fetus should be allowed to be born.

This discussion centers around an important medicolegal confrontation that is being addressed with increasing frequency in American courts. It has been brought about primarily because of advances in medical genetics and prenatal diagnosis. It is a special kind of question that the courts are facing. In short, it is the question: To be or not to be?

As most of you already know, the traditional case of medical negligence—commonly called malpractice—involves the failure of a health professional to meet a certain standard of care because of omission or commission of an act which causes harm or injury to a patient. The law provides remedies in such cases if the plaintiff-patient can prove that a standard of care was breached, resulting in a harm or injury which is legally compensable and that the harm was directly linked to or caused by the breach. If all of these factors are present, then the plaintiff has made a *prima facie* case of medical malpractice. It is then incumbent on the physician-defendant to disprove the plaintiff's allegations or to show that the circumstances allowed a departure from the established standard of care.

Now let us turn to a typical legal case brought on by failure to meet the standard of care which has been established in prenatal medicine to offer amniocentesis to every pregnant woman 35 years of age or older. In *Becker v. Schwartz* [1], Mrs. Becker, a 37-year-old pregnant woman, was not advised by her obstetrician, Dr. Schwartz, that women of her age had an increased risk of bearing a child with Down syndrome. Furthermore, he did not inform her of the availability of a prenatal test to rule out a gross chromosomal abnormality in the fetus. After their affected daughter was born, Mr. and Mrs. Becker claimed that, had they known the risks, she would have had amniocentesis and a karyotype analysis of

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the fetus, and when the results showed the presence of Down syndrome, she would have elected to have an abortion. Both parents and the child sued Dr. Schwartz for the injuries they sustained as a result of his failure to warn and failure to offer diagnostic tests.

Mr. and Mrs. Becker claimed that they were denied a procreative choice to abort an abnormal fetus. The infant, through her parents as next-of-kin, claimed that she should never have been allowed to be born with grave mental and physical abnormalities.

The parents' claim is called *wrongful birth*. The child's claim is called *wrongful life*. I will return later to a discussion of these terms, but first I will satisfy your curiosity about the outcome of the *Becker v. Schwartz* case.

The trial court in New York dismissed the case, stating that New York did not recognize a cause of action for "wrongful birth" or "wrongful life." The Beckers appealed, and the intermediate appellate court reversed the trial court's decision. On the question of the right of the child to sue, claiming that it should never have been born, the court relied on a statement made by Justice Oliver Wendell Holmes in an 1884 Massachusetts case [2]. He said, "[T]here may be a conditional prospective liability to one not-yet-in-being." Holmes meant that it was conditional on live birth and that the prospective liability accrued at birth.

The physician, Dr. Schwartz, then appealed to New York's highest court of appeals, which found in favor of the doctor regarding the child's claim but upheld the parents' claim. Thus, it became the law of the entire state of New York that a child could not sue for being born in a defective condition, and this remains the law today, throughout that state. (As we shall see later, California has pursued a different course.)

This legal precedent in New York can be changed only in three ways: (1) the state legislature could enact a statute allowing a defective child to sue for its wrongful life; (2) the highest court in New York could reverse its own holding in a later case; or (3) the United States Supreme Court could recognize a legal cause of action for wrongful life.

There have been many other cases involving wrongful birth and wrongful life claims. Table 1 summarizes 27 legal cases of interest to medical geneticists [1, 3–28]. I have not included the outcomes of these cases because they vary from jury to jury, judge to judge, and state to state. The parents claimed damages for medical, hospital, nursing, and funeral expenses, the costs of rearing the defective child, the costs of special education or institutionalization, and the emotional pain and suffering caused by the child's condition. The children claimed that they should not have been born at all because their defects, which caused physical pain and suffering, could have been predicted before conception and/or detected before birth. In some cases, all claims were denied. In other cases, the mother's and/or the father's claims for economic loss were recognized. In some cases, the parents recovered damages for their emotional suffering. In four cases listed in table 1, the child's suit was upheld. I shall return to these cases later.

It is important to distinguish the nomenclature used in these cases. A tort action for "wrongful birth" is brought by the parents. It has also been called "wrongful pregnancy" and "wrongful conception," depending upon the act which is alleged

TABLE 1
LEGAL CASES OF INTEREST TO MEDICAL GENETICISTS

Name of case	Year	Diagnosis	
<i>Aquilio v. Nelson</i> [3]	1980	Erythroblastosis fetalis	Negligence during second pregnancy with knowledge of Rh incompatibility and history of previously affected child Physician failed to provide genetic counseling to 38-year-old woman concerning increased risk associated with advanced maternal age and failed to offer amniocentesis Same as <i>Becker v. Schwartz</i> Physician who took care of father through two operations and death failed to warn daughter of hereditary nature of disease and take possible corrective action. Daughter died of disease 21 years after her father's death and 9 years after having a child who is also at risk Mother, age 39 when child with Down syndrome was born, was not told that amniocentesis and elective abortion was an available reproductive alternative in 1972 Laboratory wrongfully reported couple to be non-carriers of Tay-Sachs gene after being put on notice that their technical methods were inaccurate
<i>Becker v. Schwartz</i> [1]	1978	Down syndrome	
<i>Berman v. Allen</i> [4]	1978	Down syndrome	
<i>Brubaker v. Cavanaugh</i> [5]	1982	Multiple polyposis of colon	
<i>Call v. Kezirian</i> [6]	1982	Down syndrome	
<i>Curlender v. Bio-Science Laboratories</i> [7]	1978	Tay-Sachs disease	
<i>Donadio v. Irving Memorial Hospital</i> [8]	1980	Repeated spontaneous abortions	
<i>Feigelson v. Ryan</i> [9]	1981	"Chromosomal disorder"	
<i>Gildiner v. Thomas Jefferson Hospital</i> [10]	1978	Tay-Sachs disease	Child of twelfth pregnancy born 10 weeks prematurely and permanently blinded by oxygen therapy. Physician failed to evaluate history of eight miscarriages, provide genetic counseling, and refer to specialists Patient, age 37, received artificial insemination by donor and was not informed that the pregnancy carried an increased risk of chromosomal abnormalities due to advanced maternal age Parents were known carriers of Tay-Sachs gene. Hexosaminidase A erroneously reported as normal in amniotic fluid, and parents were reassured that fetus was normal

(Table 1 continued on next page)

TABLE 1 (continued)

Name of case	Year	Diagnosis	
<i>Harbeson v. Parke-Davis</i> [11]	1983	Fetal hydatinoin syndrome	Physicians failed to inform parents of possible grave consequences to fetus because mother was taking Dilantin during pregnancy for her convulsive disorder. Two children were severely affected with fetal hydatinoin syndrome
<i>Howard v. Lecher</i> [12]	1977	Tay-Sachs disease	Physician failed to take a genetic and ethnic history, failed to offer heterozygote tests, failed to offer genetic counseling, and failed to offer prenatal diagnosis
<i>Johnson v. Yeshiva University</i> [13]	1977	Cri du chat syndrome	Parents claimed that they should have been offered amniocentesis to discover a structural chromosomal abnormality in the fetus even though they were at no increased risk and amniocentesis was not the standard of care in 1972
<i>Jorgensen v. Meade-Johnson Laboratories</i> [14]	1973	Down syndrome twins	Patient was not warned that impregnation while taking oral contraceptives might result in non-disjunction. This case turned on "strict liability" for drug safety rather than negligence
<i>Karlsons v. Guerinot</i> [15]	1977	Down syndrome	Patient's first child had "unspecified deformities." Patient not told that because of her maternal age of 37 she had an increased risk of a Down syndrome fetus
<i>Lazevnick v. Monroe County Hospital</i> [16]	1980	Erythroblastosis fetalis	Mother's blood type erroneously reported as A, Rh +, instead of O, Rh -, during first pregnancy. Wrong blood type relied upon during second pregnancy, and child was born with Rh disease
<i>Mellis v. Chicago Wesley Hospital</i> [17]	1974	Thalassemia major	Father was diagnosed as "thalassemia minor" but mother was misdiagnosed as noncarrier prior to conception
<i>Moores v. Lucas</i> [18]	1981	Larsen syndrome	Parents were falsely reassured that mother's condition was not heritable, prior to conception. Child was born with dominant form of condition
<i>Naccash v. Burger</i> [19]	1982	Tay-Sachs disease	Father's blood test was wrongly reported to be "normal" for hexosaminidase A
<i>Nelson v. Krusen</i> [20]	1982	Duchenne muscular dystrophy	After their first child suffered from muscular dystrophy, mother underwent carrier tests. Normal results were found on physical examination, EMG, and creatine phosphokinase tests and retests, and she was told she was not a carrier and her risk of having another affected child was no greater than the general population. Second son developed muscular dystrophy at age 3

<i>Ochs v. Borrelli</i> [21]	1982	"Congenital orthopedic defects"	After two children were born with congenital skeletal defects, mother underwent a tubal ligation which failed. Third child had even more severe defects
<i>Park v. Chessin</i> [22]	1978	Infantile polycystic kidneys	First child died of polycystic kidney disease 5 hrs after birth. Autopsy performed. Parents were falsely reassured that condition was not hereditary. Second child died of same condition at age 2
<i>Phillips v. United States</i> [23]	1981	Familial Down syndrome	Pregnant patient, age 23, reported to her obstetrician that she had a sister with Down syndrome. He failed to inform her that she had an increased risk and failed to offer amniocentesis and chromosome testing
<i>Renslow v. Mennonite Hospital</i> [24]	1977	Erythroblastosis fetalis	Mother, who is Rh -, was wrongfully transfused with Rh+ blood at age 13. She gave birth to affected child 8 years later
<i>Schreck v. New York</i> [25]	1981	Congenital microcephaly	First child had microcephaly and mental retardation. Sonograms and "other tests" during second pregnancy were reported as normal. Second child also had microcephaly. Parents complained that physicians failed to warn them that future children might suffer the same genetic defect as their first child
<i>Schroeder v. Perkel</i> [26]	1981	Cystic fibrosis	Pediatrician failed to diagnose cystic fibrosis in first child and failed to warn parents of hereditary nature of the condition and of the increased risks in subsequent children. Second child affected with cystic fibrosis
<i>Speck v. Finegold</i> [27]	1981	Neurofibromatosis	After two affected children were born to an affected father, he and his wife received genetic counseling and he had a vasectomy. Wife became pregnant and had an abortion. Several months later, a child was born with neurofibromatosis. Parents sued for negligence in performance of vasectomy and abortion
<i>Turpin v. Sortini</i> [28]	1982	Hereditary deafness	First child, who was totally deaf, was misdiagnosed in infancy as having normal hearing. Parents were falsely reassured prior to conception of second child, who was also born affected

to cause the harm or injury to the parents. On the other hand, a cause of action for “wrongful life” is brought by the child. (To be more accurate, the parents or any other third party may file a wrongful life suit on behalf of the child who has been injured by an alleged wrongful act.) Some authors use the term “diminished life” to refer to those children who have mental or physical defects as a result of the wrongdoing and “dissatisfied life” for those who complain that, for nonmedical reasons, they should not have been allowed to be born. An example of the latter is the complaint that the child has been stigmatized by being illegitimate, suing the father for compensation.

Many parents will complain of “wrongful birth” if a negligent act interferes with their constitutionally protected right to choose not to have children, even though the child is perfectly normal and healthy. However, the cases which concern us as geneticists are those where the child is born with congenital deformities or genetic disease. The earliest cases of wrongful birth resulting in the birth of an abnormal child involved fetal damage from maternal rubella. The doctor either failed to diagnose rubella or failed to warn the mother of its dire consequences to the fetus, thus robbing her of the choice to undergo selective abortion.

List 1 gives several negligent acts of health-care providers that may result in wrongful birth and wrongful life lawsuits. Note that some of these involve failure to act rather than wrongful acts. These are called nonfeasance (nondeeds) and malfeasance (misdeeds), respectively.

As you can imagine, there are a number of legal issues addressed in these wrongful birth/wrongful life cases. List 2 states some of the reasons judges have given for denying parents’ claims and other reasons for recognizing their claims. These reasons were written in the judicial opinions as a means of announcing why a certain outcome was reached. They are important for lawyers who must argue future cases, and they also put physicians on notice as to the proper standard of care expected of them. All of the cases listed in table 1 and all of the rationales given in lists 2 and 3 are from appellate courts. Most lower courts do not publish their opinions, and their judgments do not constitute legal precedents.

LIST 1

NEGLIGENT ACTS CLAIMED BY PLAINTIFFS IN WRONGFUL BIRTH/ WRONGFUL LIFE SUITS

Failed vasectomy
Failed tubal ligation
Failed contraception
Failed abortion
Missed diagnosis of pregnancy
Failure to take a family history
Failure to identify high risks
Failure to perform diagnostic tests
Failure to provide counseling
Misdiagnosis of previous child
Missed diagnosis of previous child
Laboratory errors

LIST 2

RATIONALE IN WRONGFUL BIRTH SUITS

Judicial reasons given when parents' claims were denied:

1. "Every child is a joy and a blessing"
2. The parents have not been harmed or injured; it is the child who suffers
3. The parents have endured emotional pain and suffering which is not usually legally compensable unless it is accompanied by physical pain and suffering. (The law calls the parents "bystanders" who witness their child's suffering)

Judicial reasons given when parents' claims were upheld:

1. For every wrong there is a legal redress
2. The physician owed a duty of care to the mother
3. The physician failed to disclose to the mother important information which bears on her reproductive decision-making
4. It will encourage accurate testing, accurate genetic histories, and accurate diagnosis
5. Prenatal diagnosis is now established as a legal standard of care

List 3 gives a number of reasons why the courts are reluctant to entertain a claim by the child that it should never have been allowed to be born. The great majority of courts dismiss the child's suit, based on one or more of these reasons. However, there are exceptions.

I shall now return to the four cases mentioned earlier, in which the child's claims were recognized.

In *Renslow v. Mennonite Hospital* [24], a 13-year-old girl was wrongly transfused with Rh-positive blood. Eight years later she gave birth to a baby girl with severe Rh disease. The infant claimed that the error made by the blood bank and the pathologist in the mother's type-and-cross-match could foreseeably lead to problems in children the woman might later bear. This is a good example of "conditional, prospective liability to one not yet in being," discussed above. Liability was recognized, and the child was awarded damages. However, this was *not* a wrongful life case in the strict sense because the infant did not make the claim that she should never have been born. Instead, she said that the transfusion to the mother 8 years before her conception caused her pain and suffering for which she should be compensated.

LIST 3

JUDICIAL REASONS FOR DENYING CHILD'S CLAIMS IN WRONGFUL LIFE SUITS

1. The court cannot compare life with defects against no life at all. This is a metaphysical quandary better left to philosophers
2. The child lacks standing to sue the physician for wrongdoing. If the wrong had not been done the child would not be here to complain
3. The court recognizes a reverence for life. Life is precious even if impaired. The sanctity of life takes precedence over the quality of life
4. Recognition of a child's claim not to be born is a matter of public policy to be resolved by the legislature, not the court
5. There is no legal right not to be born
6. There is no fundamental right to be born as a whole, functional human being
7. The physician owed a duty of care to the mother, who was the patient, but not to the fetus
8. The child's defect was not caused by the wrongful act of the physician
9. Recognition of a child's complaint would open the floodgates of litigation to all who were dissatisfied with life
10. Wrongful life actions against physicians would inevitably lead to wrongful life actions against parents

The case of *Curlender v. Bio-Science Laboratories* [7] was heard by a California intermediate appellate court. The parents submitted to tests for hexosaminidase A because they were Ashkenazi Jews. The laboratory erroneously reported both of them to be noncarriers of the Tay-Sachs gene in spite of the fact that the laboratory had been forewarned by Dr. Michael Kaback that their testing procedures were inaccurate and might lead to a tragic outcome. The court was so outraged that the laboratory did not take proper precautions after being put on notice that the court not only recognized the child's claim for wrongful life, but also allowed the jury to consider punitive damages for willful misconduct.

The most striking aspect of the *Curlender* case was a statement made by the court, *in dicta*, that a child might also have the right to sue his or her parents under certain circumstances. In a rare comment the judge stated: "If a case arose where . . . parents made a conscious choice to proceed with a pregnancy, with full knowledge that a seriously impaired infant would be born . . . we see no sound public policy which should protect those parents from being answerable for the pain, suffering, and misery which they have wrought upon their offspring."

Soon after this decision was announced there was a public outcry that under no circumstances should children ever be allowed to sue their parents for allowing them to be born, regardless of the severity of the child's abnormalities, or regardless of the parents' foreknowledge and reckless disregard of the child's potential suffering. In fact, the California legislature soon introduced a bill denying children the right to sue their parents for wrongful life, and the bill passed and was enacted into law. Some legal commentators predicted that the *Curlender* decision to allow children to sue their physicians and other health-care providers would be overturned by the California Supreme Court, as a matter against public policy. However, this was not the case.

Soon thereafter, the case of *Turpin v. Sortini* [28] was decided by the California Supreme Court. In this case, the parents were falsely reassured that their first child had normal hearing (even though she was totally deaf). They relied on the audiologist's findings and planned another child. The second child also suffered from hereditary deafness. An appellate court denied the second child's claim for wrongful life but the Supreme Court of California reversed that decision. Thus, California became the first state to recognize and uphold the wrongful life concept.

Since this presidential address was given, the Supreme Court of the State of Washington has upheld a wrongful life claim brought by two siblings who suffered from fetal hydantoin syndrome. In *Harbeson v. Parke-Davis* [11], the mother had a convulsive disorder and was treated with Dilantin throughout both pregnancies. She specifically asked her obstetricians about the teratogenic effects of her medication and was told that it might cause cleft palate and temporary hirsutism. The court found that the physicians were negligent in failing to keep abreast of the medical literature, causing the mother to rely on false information. Thus, there are now two states that recognize wrongful life suits brought by children. The reasons given by the California and Washington courts were several. There was a reliance on Justice Holmes' pronouncement of a conditional, prospective liability. The courts also pointed out that the obstetrician owes a duty to the fetus

as well as to the mother and that the child both exists and suffers. Furthermore, there should be just compensation for legal wrongs.

It is always dangerous to predict future trends in the law. But I believe that a number of factors are converging to change some very basic legal thinking in this country. So far, we have heard only rumblings from a few courts. Even California has backed off from allowing suits against parents. But I do not believe this will last long. With the health problems associated with maternal PKU, maternal alcoholism, and other known teratogens, and the increasing ability to detect diseases and defects in utero and even to correct defects by fetal medication, fetal surgery or genetic manipulation, it seems, to me at least, that parental rights to reproduce will diminish as parental responsibilities to unborn offspring increase. There may even be cases of intentional, rather than negligent, fetal abuse to report to you several years from now. No longer are we playing genetic roulette. As Roy Schmickel once remarked, the medical geneticist is rapidly changing from a bookie to a fixer. Future generations will be the beneficiaries of our increasing predictive powers and therapeutic tinkering. Parenthood may become a privilege to be cherished rather than a right to be exercised even when a child is harmed.

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